National Clinical Guidelines Centre

Motor Neurone Disease

Search strategies appendix

Clinical guideline

Appendices

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Disclaimer

Healthcare professionals are expected to take NICE clinical guidelines fully into account when exercising their clinical judgement. However, the guidance does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of each patient, in consultation with the patient and, where appropriate, their guardian or carer.

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Search strategies used for the motor neurone disease guideline are outlined below and were run in accordance with the methodology in the NICE guidelines manual 2012.{NICE2012} All searches were run up to **18 May 2015** unless otherwise stated. Any studies added to the databases after this date (even if they were published prior to this date) were not included unless specifically stated in the text. We do not routinely search for electronic, ahead of print or 'online early' publications. Where possible searches were limited to retrieve material published in English.

Table 1: Database date parameters

Database	Dates searched
Medline	1946 – 18th May 2015
Embase	1974 – 18th May 2015
The Cochrane Library	Cochrane Reviews to 2015 Issue 5 of 12 CENTRAL to 2015 Issue 4 of 12 DARE, HTA and NHSEED to 2015 Issue 2 of 4
CINAHL	1960-18th May 2015
PsycINFO (OVID)	1967-31st March 2015
PsycINFO (ProQuest)	2014-18th May 2015

Searches for the **clinical reviews** were run in Medline (OVID) and Embase (OVID). Additional searches were run in the Cochrane Library, CINAHL (EBSCO) and PsycInfo (OVID and ProQuest) for some questions. See Table 2.

Table 2: Databases searched in addition to Medline and Embase

Question	Question number	Databases
AAC	A.4.3	Cochrane, CINAHL, PsycINFO
Breathlessness	A.4.4	Cochrane
Cognitive assessment	A.4.5	Cochrane, CINAHL, PsycINFO
Co-ordination of care	A.4.6	Cochrane, CINAHL, PsycINFO
Cough	A.4.7	Cochrane, CINAHL
Discontinuation of NIV	A.4.8	CINAHL, PsycINFO
End of life	A.4.9	CINAHL, PsycINFO
Equipment for muscle weakness	A.4.10	CINAHL
Frequency of assessment	A.4.11	Cochrane
Knowledge for communicating diagnosis	A.4.13	CINAHL, PsycINFO
Muscle weakness	A.4.14	Cochrane, CINAHL
Nutrition	A.4.15	Cochrane, CINAHL, PsycINFO
Population only search 1	A.4.1	Cochrane, CINAHL, PsycINFO
Population only search 2	A.4.2	Cochrane, CINAHL
Psychological support	A.4.16	CINAHL, PsycINFO
Risk factors	A.4.17	None
Saliva	A.4.18	Cochrane

Question	Question number	Databases
Social care	A.4.19	CINAHL, PsycINFO
Timeliness of diagnosis	A.4.20	CINAHL, PsycINFO
Timing of gastronomy	A.4.12	Cochrane, CINAHL, PsycINFO

Searches for **intervention and diagnostic studies** were usually constructed using a PICO format where Population (P) terms were combined with Intervention (I) and sometimes Comparison (C) terms. An intervention can be a drug, a procedure or a diagnostic test. Outcomes (O) are rarely used in search strategies for interventions. Search filters were also added to the search where appropriate.

Searches for **prognostic studies** were usually constructed combining population terms with prognostic variable terms and sometimes outcomes. Search filters were added to the search where appropriate.

Searches for the **health economic reviews** were run in Medline (OVID), Embase (OVID), the NHS Economic Evaluations Database (NHS EED), the Health Technology Assessment (HTA) database and the Health Economic Evaluation Database (HEED). NHS EED and HTA databases were hosted by the Centre for Research and Dissemination (CRD). The Health Economic Evaluation Database (HEED) ceased production in 2014 with access ceasing in January 2015. For the final dates of HEED searches, please see individual economic questions.

For Medline and Embase an economic filter (instead of a study type filter) was added to the same clinical search strategy. Searches in NHS EED and HEED were constructed using population terms only.

A.2   Population search strategies

A.2.1   Standard population

This search was used in all clinical questions except questions A.4.4 and A.4.18.

Medline search term

1.	motor neuron disease/
2.	amyotrophic lateral sclerosis/
3.	bulbar palsy, progressive/
4.	exp *motor neuron/
5.	(motor neuron* or moto neuron* or motoneuron* or motorneuron* or moto-neuron* or motor-neuron*).ti,ab
6.	((primary or amyotrophic) adj lateral scleros*).ti,ab.
7.	(progressive adj (muscular atroph* or bulbar pals*)).ti,ab.
8.	(pseudopolyneur* or pseudo-polyneur* or psuedo polyneur*).ti,ab.
9.	((pseudobulbar or pseudo-bulbar or pseudo bulbar) adj pals*).ti,ab.
10.	((bulbar or respirat* or limb) adj onset*).ti,ab.
11.	lou gehrig*.ti,ab.
12.	((anterior or ventral) adj (horn or column) adj3 (disease* or disorder*)).ti,ab.
13.	(flail* adj (arm* or leg*) adj (syndrome* or disorder*)).ti,ab.
14.	(guam adj (disease* or disorder* or syndrome*)).ti,ab.
15.	monomelic amyotroph*.ti,ab.
16.	frontotemporal dementia/

17.	((frontotemporal or fronto temporal or fronto-temporal) adj dement*).ti,ab.
18.	or/1-17

Embase search terms

1.	exp *motor neuron disease/
2.	*bulbar paralysis/
3.	*motoneuron/
4.	(motor neuron* or moto neuron* or motoneuron* or motorneuron* or moto-neuron* or motor-neuron*).ti,ab.
5.	((primary or amyotrophic) adj lateral scleros*).ti,ab.
6.	(progressive adj (muscular atroph* or bulbar pals*)).ti,ab.
7.	(pseudopolyneur* or pseudo-polyneur* or psuedo polyneur*).ti,ab.
8.	((pseudobulbar or pseudo-bulbar or pseudo bulbar) adj pals*).ti,ab.
9.	((bulbar or respirat* or limb) adj onset*).ti,ab.
10.	lou gehrig*.ti,ab.
11.	((anterior or ventral) adj (horn or column) adj3 (disease* or disorder*)).ti,ab.
12.	(flail* adj (arm* or leg*) adj (syndrome* or disorder*)).ti,ab.
13.	(guam adj (disease* or disorder* or syndrome*)).ti,ab.
14.	monomelic amyotroph*.ti,ab.
15.	exp *frontotemporal dementia/
16.	((frontotemporal or fronto temporal or fronto-temporal) adj dement*).ti,ab.
17.	or/1-16

Cochrane search terms

#1.	MeSH descriptor: [motor neuron disease] explode all trees
#2.	MeSH descriptor: [motor neurons] explode all trees
#3.	(motor neuron* or moto neuron* or motoneuron* or motorneuron* or moto-neuron* or motor-neuron*):ti,ab
#4.	lateral next scleros*:ti,ab
#5.	(progressive muscular atroph*) or (progressive bulbar pals*):ti,ab
#6.	(pseudopolyneur* or pseudo-polyneur* or psuedo polyneur*) .ti,ab.
#7.	(pseudobulbar or pseudo-bulbar or pseudo bulbar):ti,ab
#8.	((bulbar or respirat* or limb) next onset*):ti,ab
#9.	lou gehrig*:ti,ab
#10.	(anterior next (horn or column)):ti,ab
#11.	(ventral next (horn or column)):ti,ab
#12.	(flail* arm*) or flail* leg*:ti,ab
#13.	(guam and (disease* or disorder* or syndrome*)):ti,ab
#14.	monomelic amyotroph*:ti,ab
#15.	MeSH descriptor: [frontotemporal dementia] explode all trees
#16.	((frontotemporal or fronto temporal or fronto-temporal) and dement*):ti,ab
#17.	{or #1-#16}

CINAHL search terms

S1.	(MH "motor neuron diseases+")
S2.	(MH "amyotrophic lateral sclerosis")
S3.	(MH "bulbar palsy, progressive+")

S4.	(mm "motor neurons+")
S5.	motor neuron* or moto neuron* or motoneuron* or motorneuron* or moto-neuron* or motor-neuron*
S6.	primary n1 lateral scleros* or amyotrophic n1 lateral scleros*
S7.	progressive n1 muscular atroph* or progressive n1 bulbar pals*
S8.	pseudopolyneur* or pseudo-polyneur* or psuedo polyneur
S9.	pseudobulbar n1 pals* or pseudo-bulbar n1 pals* or pseudo bulbar n1 pals*
S10.	bulbar n1 onset* or respirat* n1 onset* or limb n1 onset*
S11.	lou gehrig*
S12.	anterior horn n3 disease* or anterior horn n3 disorder* or anterior column n3 disease* or anterior column n3 disorder* or ventral horn n3 disease* or ventral horn n3 disorder* or ventral column n3 disease* or ventral column n3 disorder*
S13.	flail* arm* syndrome* or flail* arm* disorder* or flail* leg* syndrome* or flail* leg* disorder*
S14.	guam disease* or guam disorder* or guam syndrome*
S15.	monomelic amyotroph*
S16.	frontotemporal dement* and fronto temporal dement* and fronto-temporal dement*
S17.	S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16

PsycINFO (Ovid) search terms

1.	exp motor neurons/ or exp amyotrophic lateral sclerosis/
2.	(motor neuron* or moto neuron* or motoneuron* or motorneuron* or moto-neuron* or motor-neuron*).ti,ab
3.	((primary or amyotrophic) adj lateral scleros*).ti,ab.
4.	(progressive adj (muscular atroph* or bulbar pals*)).ti,ab.
5.	(pseudopolyneur* or pseudo-polyneur* or psuedo polyneur*).ti,ab.
6.	((pseudobulbar or pseudo-bulbar or pseudo bulbar) adj pals*).ti,ab.
7.	((bulbar or respirat* or limb) adj onset*).ti,ab.
8.	lou gehrig*.ti,ab.
9.	((anterior or ventral) adj (horn or column) adj3 (disease* or disorder*)).ti,ab.
10.	(flail* adj (arm* or leg*) adj (syndrome* or disorder*)).ti,ab.
11.	(guam adj (disease* or disorder* or syndrome*)).ti,ab.
12.	monomelic amyotroph*.ti,ab.
13.	((frontotemporal or fronto temporal or fronto-temporal) adj dement*).ti,ab.
14.	or/1-13

PsycINFO (ProQuest) search terms

1.	((su.exact.explode("motor neurons") or su.exact.explode("amyotrophic lateral sclerosis") or ti,ab(motoneuron* or motorneuron* or moto-neuron* or motor-neuron*) or ti,ab((primary or amyotrophic) near/1 lateral scleros*) or ti,ab(pseudopolyneur* or pseudo-polyneur*) or ti,ab((pseudobulbar or pseudo-bulbar) near/1 pals*) or ti,ab((bulbar or respirat* or limb) near/1 onset*) or ti,ab((anterior or ventral) near/1 (horn or column) near/3 (disease* or disorder*)) or ti,ab(flail* near/1 (arm* or leg*) near/1 (syndrome* or disorder*)) or ti,ab(guam near/1 (disease* or disorder* or syndrome*)) or ti,ab(monomelic amyotroph*) or ti,ab((frontotemporal or fronto-temporal) near/1 dement*) or ti,ab((muscular-atroph*) or (bulbar-pals*) near/1 progressive) or ti,ab(lou-gehrig*))

A.2.2 Neuromuscular disease

This search was used in question A.4.7 in conjunction with the standard population.

Medline search term

1.	exp neuromuscular diseases/
2.	randomized controlled trial.pt.
3.	controlled clinical trial.pt.
4.	randomi#ed.ab.
5.	placebo.ab.
6.	randomly.ab.
7.	clinical trials as topic.sh.
8.	trial.ti.
9.	or/2-8
10.	1 and 9

Embase search term

1.	exp neuromuscular diseases/
2.	random*.ti,ab.
3.	factorial*.ti,ab.
4.	(crossover* or cross over*).ti,ab.
5.	((doubl* or singl*) adj blind*).ti,ab.
6.	(assign* or allocat* or volunteer* or placebo*).ti,ab.
7.	crossover procedure/
8.	single blind procedure/
9.	randomized controlled trial/
10.	double blind procedure/
11.	or/2-10
12.	1 and 11

Cochrane search term

1.	MeSH descriptor: [neuromuscular diseases] explode all trees

CINAHL search term

1.	(MH "neuromuscular diseases+")

A.3 Study filter search terms

A.3.1 Systematic reviews (SR) search terms

Medline search terms

1.	meta-analysis/
2.	meta-analysis as topic/
3.	(meta analy* or metanaly* or metaanaly*).ti,ab.
4.	((systematic* or evidence*) adj3 (review* or overview*)).ti,ab.
5.	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
6.	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
7.	(search* adj4 literature).ab.
8.	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
9.	cochrane.jw.

10.	or/1-9

Embase search terms

1.	systematic review/
2.	meta-analysis/
3.	(meta analy* or metanaly* or metaanaly*).ti,ab.
4.	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
5.	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
6.	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
7.	(search* adj4 literature).ab.
8.	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
9.	((pool* or combined) adj2 (data or trials or studies or results)).ab.
10.	cochrane.jw.
11.	or/1-10

PsycInfo (Ovid) search terms

1.	"review"/ or review.pt. or review.ti. or literature review.md.
2.	(systematic or evidence* or methodol* or quantitativ*).ti,ab.
3.	1 and 2
4.	meta-analysis/
5.	(meta-analys* or metanalys* or metaanalys* or meta analys*).ti,ab.
6.	((systematic or evidence* or methodol* or quantitativ*) adj3 (review* or overview*)).ti,ab.
7.	((pool* or combined or combining) adj2 (data or trials or studies or results)).ti,ab.
8.	(systematic or meta*).pt. or (meta analysis or systematic review).md.
9.	or/3-8

PsycInfo (ProQuest) search terms

1.	((SU.EXACT("Literature Review") or RTYPE(review) or ti(review) or me(literature review)) AND (ti,ab(systematic or evidence or methodol* or quantitative*))) or (SU.EXACT("Meta Analysis") or ti,ab(meta-analys* or metanalys* or metaanalys* or meta analys*) or ti,ab((systematic or evidence* or methodol* or quantitative*) near/3 (review* or overview*)) or ti,ab((pool* or combined or combining) near/2 (data or trials or studies or results)) or RTYPE(systematic or meta*) or ME(meta analysis or systematic review))

A.3.2 Randomised controlled trials (RCT) search terms

Medline search terms

1.	randomized controlled trial.pt.
2.	controlled clinical trial.pt.
3.	randomi#ed.ab.
4.	placebo.ab.
5.	randomly.ab.
6.	clinical trials as topic.sh.
7.	trial.ti.
8.	or/1-7

Embase search terms

1.	random*.ti,ab.

2.	factorial*.ti,ab.
3.	(crossover* or cross over*).ti,ab.
4.	((doubl* or singl*) adj blind*).ti,ab.
5.	(assign* or allocat* or volunteer* or placebo*).ti,ab.
6.	crossover procedure/
7.	double blind procedure/
8.	single blind procedure/
9.	randomized controlled trial/
10.	or/1-9

PsycInfo (Ovid) search terms

1.	exp clinical trial/
2.	randomi*.ti,ab.
3.	((clinical or control*) adj3 trial*).ti,ab.
4.	((singl* or doubl* or trebl* or tripl*) adj5 (blind* or mask*)).ti,ab.
5.	(volunteer* or control group or controls).ti,ab.
6.	placebo/ or placebo*.ti,ab.
7.	or/1-6

PsycInfo (ProQuest) search terms

1.	(su.exact.explode("clinical trials") or ti,ab((clinical or control*) near/3 trial*) or ti,ab((singl* or doubl* or trebl* or tripl*) near/5 (blind* or mask*)) or ti,ab(volunteer* or control-group or controls) or su.exact("placebo") or ti,ab(placebo*))

A.3.3 Observational studies (OBS) search terms

Medline search terms

1.	epidemiologic studies/
2.	exp case control studies/
3.	exp cohort studies/
4.	cross-sectional studies/
5.	case control.ti,ab.
6.	(cohort adj (study or studies or analys*)).ti,ab.
7.	((follow up or observational or uncontrolled or non randomi#ed or nonrandomi#ed or epidemiologic*) adj (study or studies)).ti,ab.
8.	((longitudinal or retrospective or prospective or cross sectional) and (study or studies or review or analys* or cohort*)).ti,ab.
9.	or/1-8

Embase search terms

1.	clinical study/
2.	exp case control study/
3.	family study/
4.	longitudinal study/
5.	retrospective study/
6.	prospective study/
7.	cross-sectional study/

8.	cohort analysis/
9.	follow-up/
10.	cohort*.ti,ab.
11.	9 and 10
12.	case control.ti,ab.
13.	(cohort adj (study or studies or analys*)).ti,ab.
14.	((follow up or observational or uncontrolled or non randomi#ed or nonrandomi#ed or epidemiologic*) adj (study or studies)).ti,ab.
15.	((longitudinal or retrospective or prospective or cross sectional) and (study or studies or review or analys* or cohort*)).ti,ab.
16.	or/1-8,11-15

PsycInfo (Ovid) search terms

1.	exp longitudinal studies/ or exp followup studies/
2.	(cohort adj (study or studies or analys*)).ti,ab.
3.	((follow up or observational or uncontrolled or non randomi#ed or nonrandomi#ed or epidemiologic*) adj (study or studies)).ti,ab.
4.	((longitudinal or retrospective or prospective or cross sectional) and (study or studies or review or analys* or cohort*)).ti,ab.
5.	or/1-4

PsycInfo (ProQuest) search terms

1.	(su.exact.explode("longitudinal studies") or su.exact.explode("followup studies") or ti,ab(cohort near/1 (study or studies or analys*)) or ti,ab((follow-up or observational or uncontrolled or non-randomi?ed or nonrandomi?ed or epidemiologic*) near/1 (study or studies)) or ti,ab((longitudinal or retrospective or prospective or cross-section) and (study or studies or review or analys* or cohort*)))

A.3.4 Qualitative reviews (QUAL) search terms

Medline search terms

1.	qualitative research/ or narration/ or exp interviews as topic/ or exp questionnaires/ or health care surveys/
2.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
3.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
4.	or/1-3

Embase search terms

1.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
2.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
3.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
4.	or/1-3

CINAHL search terms

1.	(MH "qualitative studies+")
2.	(MH "qualitative validity+")
3.	(MH "interviews+") or (MH "focus groups") or (MH "surveys") or (MH "questionnaires+")
4.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
5.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*)
6.	S1 or S2 or S3 or S4 or S5

PsycINFO (Ovid) search terms

1.	qualitative research/ or narration/ or exp interviews as topic/ or exp questionnaires/ or health care surveys/
2.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
3.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
4.	or/1-3

PsycINFO (Ovid) search terms

1.	((su.exact.explode("qualitative research") or su.exact("narratives") or su.exact.explode("questionnaires") or su.exact.explode("interviews") or su.exact.explode("health care services") or ti,ab(qualitative or interview* or focus group* or theme* or questionnaire* or survey*) or ti,ab(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* near/3 analys*) or theoretical-sampl* or purposive-sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*)))

A.3.5 Health economics (HE) search terms

Medline search terms

1.	economics/
2.	value of life/
3.	exp "costs and cost analysis"/
4.	exp economics, hospital/
5.	exp economics, medical/
6.	economics, nursing/
7.	economics, pharmaceutical/
8.	exp "fees and charges"/
9.	exp budgets/
10.	budget*.ti,ab.
11.	cost*.ti.
12.	(economic* or pharmaco?economic*).ti.
13.	(price* or pricing*).ti,ab.
14.	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.

15.	(financ* or fee or fees).ti,ab.
16.	(value adj2 (money or monetary)).ti,ab.
17.	or/1-16

Embase search terms

1.	health economics/
2.	exp economic evaluation/
3.	exp health care cost/
4.	exp fee/
5.	budget/
6.	funding/
7.	budget*.ti,ab.
8.	cost*.ti.
9.	(economic* or pharmaco?economic*).ti.
10.	(price* or pricing*).ti,ab.
11.	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
12.	(financ* or fee or fees).ti,ab.
13.	(value adj2 (money or monetary)).ti,ab.
14.	or/1-13

A.3.6   Quality of life (QOL) search terms

Medline search terms

1.	quality-adjusted life years/
2.	sickness impact profile/
3.	(quality adj2 (wellbeing or well-being)).ti,ab.
4.	sickness impact profile.ti,ab.
5.	disability adjusted life.ti,ab.
6.	(qal* or qtime* or qwb* or daly*).ti,ab.
7.	(euroqol* or eq5d* or eq 5d*).ti,ab.
8.	(qol* or hql* or hqol* or h qol* or hrqol* or hr qol*).ti,ab.
9.	(health utility* or utility score* or disutilit*).ti,ab.
10.	(hui or hui1 or hui2 or hui3).ti,ab.
11.	health* year* equivalent*.ti,ab.
12.	(hye or hyes).ti,ab.
13.	rosser.ti,ab.
14.	(willingness to pay or time tradeoff or time trade off or tto or standard gamble*).ti,ab.
15.	(sf36 or sf 36 or short form 36 or shortform 36 or shortform36).ti,ab.
16.	(sf20 or sf 20 or short form 20 or shortform 20 or shortform20).ti,ab.
17.	(sf12 or sf 12 or short form 12 or shortform 12 or shortform12).ti,ab.
18.	(sf8 or sf 8 or short form 8 or shortform 8 or shortform8).ti,ab.
19.	(sf6 or sf 6 or short form 6 or shortform 6 or shortform6).ti,ab.
20.	or/1-19

Embase search terms

1.	quality adjusted life year/
2.	"quality of life index"/

3.	short form 12/ or short form 20/ or short form 36/ or short form 8/
4.	sickness impact profile/
5.	(quality adj2 (wellbeing or well-being)).ti,ab.
6.	sickness impact profile.ti,ab.
7.	disability adjusted life.ti,ab.
8.	(qal* or qtime* or qwb* or daly*).ti,ab.
9.	(euroqol* or eq5d* or eq 5d*).ti,ab.
10.	(qol* or hql* or hqol* or h qol* or hrqol* or hr qol*).ti,ab.
11.	(health utility* or utility score* or disutilit*).ti,ab.
12.	(hui or hui1 or hui2 or hui3).ti,ab.
13.	health* year* equivalent*.ti,ab.
14.	(hye or hyes).ti,ab.
15.	rosser.ti,ab.
16.	(willingness to pay or time tradeoff or time trade off or tto or standard gamble*).ti,ab.
17.	(sf36 or sf 36 or short form 36 or shortform 36 or shortform36).ti,ab.
18.	(sf20 or sf 20 or short form 20 or shortform 20 or shortform20).ti,ab.
19.	(sf12 or sf 12 or short form 12 or shortform 12 or shortform12).ti,ab.
20.	(sf8 or sf 8 or short form 8 or shortform 8 or shortform8).ti,ab.
21.	(sf6 or sf 6 or short form 6 or shortform 6 or shortform6).ti,ab.
22.	or/1-21

A.3.7 Health economic modelling (MOD) search terms

Medline search terms

1.	exp models, economic/
2.	*models, theoretical/
3.	*models, organizational/
4.	markov chains/
5.	monte carlo method/
6.	exp decision theory/
7.	(markov* or monte carlo).ti,ab.
8.	econom* model*.ti,ab.
9.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
10.	or/1-9

Embase search terms

1.	statistical model/
2.	exp economic aspect/
3.	1 and 2
4.	*theoretical model/
5.	*nonbiological model/
6.	stochastic model/
7.	decision theory/
8.	decision tree/
9.	monte carlo method/
10.	(markov* or monte carlo).ti,ab.

11.	econom* model*.ti,ab.
12.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
13.	or/3-12

A.3.8 Excluded study designs and publication types

The following study designs and publication types were removed from retrieved results using the NOT operator.

Medline search terms

1.	letter/
2.	editorial/
3.	news/
4.	exp historical article/
5.	anecdotes as topic/
6.	comment/
7.	case report/
8.	(letter or comment*).ti.
9.	or/1-8
10.	randomized controlled trial/ or random*.ti,ab.
11.	9 not 10
12.	animals/ not humans/
13.	exp animals, laboratory/
14.	exp animal experimentation/
15.	exp models, animal/
16.	exp rodentia/
17.	(rat or rats or mouse or mice).ti.
18.	or/11-17

Embase search terms

1.	letter.pt. or letter/
2.	note.pt.
3.	editorial.pt.
4.	case report/ or case study/
5.	(letter or comment*).ti.
6.	or/1-5
7.	randomized controlled trial/ or random*.ti,ab.
8.	6 not 7
9.	animal/ not human/
10.	nonhuman/
11.	exp animal experiment/
12.	exp experimental animal/
13.	animal model/
14.	exp rodent/
15.	(rat or rats or mouse or mice).ti.
16.	or/8-15

PsycINFO (Ovid) search terms

1.	animals/ not humans/
2.	exp rodents/ or exp mice/
3.	(rat or rats or mouse or mice).ti.
4.	or/1-3

PsycINFO (Ovid) search terms

1.	(su.exact.explode("rodents") or su.exact.explode("mice") or (su.exact("animals") not (su.exact("human males") or su.exact("human females"))) or ti(rat or rats or mouse or mice))

A.4 Searches for specific questions

A.4.1 Population only search 1

Searches for the following three questions were run as one search:

1. What is the clinical and cost-effectiveness of augmentative and alternative communication systems for supporting communication in people with MND?
2. What is the optimum frequency of assessing cognitive function in patients with MND?
3. What are the most clinically and cost-effective methods for maintaining nutritional intake and managing weight in people with MND for whom a gastrostomy is not appropriate?

Search constructed by combining the columns in the following table using the AND Boolean operator. Exclusion filter applied using NOT Boolean operator.

Population	Intervention or exposure	Comparison	Study design filter	Date parameters and other limits
Adults (aged 18 and over) with motor neurone disease (A.2.1)			The following filters were used in Medline, Embase and PsycINFO only: OBS, RCT, SR	See Table 1 English only Exclusion filter applied in Medline, Embase and PsycINFO

A.4.2 Population only search 2

Searches for the following four questions were run as one search:

4. What specific MND knowledge do patients, their carers and health professionals consider is required in order to communicate diagnosis of MND, its prognosis, and choices of ongoing care appropriately?
5. What psychological support is needed for people with MND and their families and carers?
6. What are the social care support needs of people with MND and their families and carers?
7. What factors impact upon timeliness of diagnosis in people with MND in the UK?

Search constructed by combining the columns in the following table using the AND Boolean operator. Exclusion filter applied using NOT Boolean operator.

Population	Intervention or exposure	Comparison	Study design filter	Date parameters and other limits
Adults (aged 18 and over) with motor neurone disease (A.2.1)			The following filters were used in Medline, Embase, CINAHL and PsycINFO only: QUAL	See Table 1 English only Exclusion filter applied in Medline, Embase

Population	Intervention or exposure	Comparison	Study design filter	Date parameters and other limits
				and PsycINFO

A.4.3 Augmentative and alternative communication (AAC)

See A.4.1

A.4.4 Breathlessness

8. What is the clinical and cost-effectiveness of pharmacological treatments for managing breathing difficulties in people with MND?

Search constructed by combining the columns in the following table using the AND Boolean operator and by combining the rows using the OR Boolean operator. Exclusion filter applied using NOT Boolean operator.

Search	Population	Intervention or exposure	Study design filter	Date parameters and other limits
A		Pharmacological treatments for managing breathing difficulties	The following filters were used in Medline and Embase only: RCT, SR	See Table 1 English only Exclusion filter applied in Medline and Embase
B	Adults (aged 18 and over) with motor neurone disease (A.2.1)		The following filters were used in Medline and Embase only: OBS	Same as search A

Medline search terms

1.	exp diazepam/ or lorazepam/ or midazolam/ or clonazepam/
2.	heroin/ or morphine/
3.	oxycodone/
4.	exp fentanyl/
5.	(diazepam or lorazepam or midazolam or rimapan or tensium or dialar of diazemuls).ti,ab.
6.	(morphine or diamorphine or oxycodone or fentanyl or oramorph or sevredol or filnarine or morphgesic or mst continus or zomorph or mxl or cyclimorph or oxynorm or dolocodon or longtec or oxycontin or targinact or abstral or effentora or actiq or instanyl or pecfent or fencino or fentalis or matrifen or mezolar or osmanil or tilofyl or victanyl or durogesic or clonazepam or rivotil).ti,ab.
7.	or/1-6
8.	*dyspnea/
9.	dyspn?ea.ti,ab.
10.	((difficult* or labo?r* or short*) adj2 breath*).ti,ab.
11.	breathlessness.ti,ab.
12.	or/8-11
13.	7 and 12

Embase search terms

1.	*diazepam/ or *lorazepam/ or *midazolam/ or *clonazepam/
2.	*diamorphine/ or *morphine/ or *oxycodone/ or *fentanyl/
3.	(diazepam or lorazepam or midazolam or rimapan or tensium or dialar of diazemuls).ti,ab.

4.	(morphine or diamorphine or oxycodone or fentanyl or oramorph or sevredol or filnarine or morphgesic or mst continus or zomorph or mxl or cyclimorph or oxynorm or dolocodon or longtec or oxycontin or targinact or abstral or effentora or actiq or instanyl or pecfent or fencino or fentalis or matrifen or mezolar or osmanil or tilofyl or victanyl or durogesic or clonazepam or rivotil).ti,ab.
5.	or/1-4
6.	exp *dyspnea/
7.	dyspn?ea.ti,ab.
8.	((difficult* or labo?r* or short*) adj2 breath*).ti,ab.
9.	breathlessness.ti,ab.
10.	or/6-9
11.	5 and10

Cochrane search terms

#1.	MeSH descriptor: [diazepam] explode all trees
#2.	MeSH descriptor: [lorazepam] explode all trees
#3.	MeSH descriptor: [midazolam] explode all trees
#4.	MeSH descriptor: [clonazepam] explode all trees
#5.	MeSH descriptor: [heroin] explode all trees
#6.	MeSH descriptor: [morphine] explode all trees
#7.	MeSH descriptor: [oxycodone] explode all trees
#8.	MeSH descriptor: [fentanyl] explode all trees
#9.	(diazepam or lorazepam or midazolam or rimapan or tensium or dialar of diazemuls):ti,ab
#10.	(morphine or diamorphine or oxycodone or fentanyl or oramorph or sevredol or filnarine or morphgesic or mst continus or zomorph or mxl or cyclimorph or oxynorm or dolocodon or longtec or oxycontin or targinact or abstral or effentora or actiq or instanyl or pecfent or fencino or fentalis or matrifen or mezolar or osmanil or tilofyl or victanyl or durogesic or clonazepam or rivotil)
#11.	{or #1-#10}
#12.	MeSH descriptor: [dyspnea] explode all trees
#13.	(dyspnea or dyspnoea):ti,ab
#14.	((difficult* or labo?r* or short*) near/2 breath*):ti,ab
#15.	breathlessness:ti,ab
#16.	{or #12-#15}
#17.	#11 and #16

A.4.5 Cognitive assessment

See A.4.1

A.4.6 Co-ordination of care

9. What is the most clinically and cost-effective approach for coordinating care and support across health and social care for people with MND and their families and carers?

Search constructed by combining the columns in the following table using the AND Boolean operator. Exclusion filter applied using NOT Boolean operator.

Population	Intervention or exposure	Comparison	Study design filter	Date parameters and other limits
Adults (aged 18 and over) with	Co-ordination of			See Table 1

	Population	Intervention or exposure	Comparison	Study design filter	Date parameters and other limits
	motor neurone disease (A.2.1)	care			English only Exclusion filter applied in Medline, Embase and PsycINFO

Medline search terms

1.	exp patient care team/ or exp nursing, team/
2.	interdisciplinary communication/
3.	"continuity of patient care"/
4.	"delivery of health care, integrated"/
5.	exp *interprofessional relations/
6.	patient care planning/ or critical pathways/
7.	case management/
8.	(interdisciplinary or inter-disciplinary or multidisciplinary or multi-disciplinary or multi-professional or multiprofessional or MDC or MDT or IDT).ti,ab.
9.	(key-worker* or key worker* or keyworker*).ti,ab.
10.	((continuity or continuum or co-ordinat* or plan* or pathway*) adj2 (care or service*)).ti,ab.
11.	((integrated or collaborative or manage*) adj2 (healthcare or service* or care or team*)).ti,ab.
12.	case management.ti,ab.
13.	or/1-12

Embase search terms

1.	exp *patient care/
2.	exp *team nursing/
3.	*interdisciplinary communication/
4.	*integrated health care system/
5.	*teamwork/
6.	*patient care planning/
7.	*clinical pathway/
8.	*case management/
9.	(interdisciplinary or inter-disciplinary or multidisciplinary or multi-disciplinary or multi-professional or multiprofessional or MDC or MDT or IDT).ti,ab.
10.	(key-worker* or key worker* or keyworker*).ti,ab.
11.	((continuity or continuum or co-ordinat* or plan* or pathway*) adj2 (care or service*)).ti,ab.
12.	((integrated or collaborative or manage*) adj2 (healthcare or service* or care or team*)).ti,ab.
13.	case management.ti,ab.
14.	or/1-13

Cochrane search terms

#1.	MeSH descriptor: [Patient Care Team] explode all trees
#2.	MeSH descriptor: [Nursing, Team] explode all trees
#3.	MeSH descriptor: [Interdisciplinary Communication] explode all trees
#4.	MeSH descriptor: [continuity of patient care] explode all trees
#5.	MeSH descriptor: [delivery of health care, integrated] explode all trees
#6.	MeSH descriptor: [interprofessional relations] explode all trees

#7.	MeSH descriptor: [patient care planning] explode all trees
#8.	MeSH descriptor: [critical pathways] explode all trees
#9.	MeSH descriptor: [case management] explode all trees
#10.	(interdisciplinary or inter-disciplinary or multidisciplinary or multi-disciplinary or multi-professional or multiprofessional or MDC or MDT or IDT):ti,ab
#11.	(key-worker* or key worker* or keyworker*):ti,ab
#12.	((continuity or continuum or co-ordinat* or plan* or pathway*) near/2 (care or service*)):ti,ab
#13.	((integrated or collaborative or manage*) near/2 (healthcare or service* or care or team*)):ti,ab
#14.	case management.ti,ab.
#15.	{or #1-#14}

CINAHL search terms

S1.	(MH "multidisciplinary care team+")
S2.	(MH "team nursing")
S3.	(MH "continuity of patient care+")
S4.	(MH "health care delivery, integrated")
S5.	(MH "interprofessional relations+")
S6.	(MH "patient care plans+")
S7.	(MH "critical path")
S8.	(MH "case management")
S9.	interdisciplinary or inter-disciplinary or multidisciplinary or multi-disciplinary or multi-professional or multiprofessional or MDC or MDT or IDT
S10.	key-worker* or key worker* or keyworker*
S11.	continuity n/2 care or continuity n2 service* or continuum n2 care or continuum n2 service* or co-ordinat* n2 care or co-ordinat* n2 service* or plan* n2 care or plan* n2 service* or pathway* n2 care or pathway* n2 service*
S12.	integrated n2 healthcare or integrated n2 service* or integrated n2 care or integrated n2 team*
S13.	collaborative n2 healthcare or collaborative n2 service* or collaborative n2 care or collaborative n2 team*
S14.	manage* n2 healthcare or manage* n2 service* or manage* n2 care or manage* n2 team*
S15.	case management
S16.	S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9 or S10 or S11 or S12 or S13 or S14 or S15

PsycINFO (Ovid) search terms

1.	exp health care delivery/
2.	exp teams/ or exp work teams/
3.	exp interdisciplinary treatment approach/
4.	exp integrated services/
5.	exp treatment planning/
6.	exp case management/
7.	(interdisciplinary or inter-disciplinary or multidisciplinary or multi-disciplinary or multi-professional or multiprofessional or MDC or MDT or IDT).ti,ab.
8.	(key-worker* or key worker* or keyworker*).ti,ab.
9.	((continuity or continuum or co-ordinat* or plan* or pathway*) adj2 (care or service*)).ti,ab.
10.	((integrated or collaborative or manage*) adj2 (healthcare or service* or care or team*)).ti,ab.
11.	case management.ti,ab.

12.	or/1-11

PsycINFO (ProQuest) search terms

1.	(su.exact.explode("health care delivery") or su.exact.explode("teams") or su.exact.explode("work teams") or su.exact.explode("interdisciplinary treatment approach") or su.exact("integrated services") or su.exact("treatment planning") or ti,ab(interdisciplinary or inter-disciplinary or multidisciplinary or multi-disciplinary or multi-professional or multiprofessional or MDC or MDT or IDT) or ti,ab(key-worker* or keyworker*) or ti,ab((continuity or continuum or co-ordinat* or plan* or pathway*) near/2 (care or service*)) or ti,ab((integrated or collaborative or manage*) near/2 (healthcare or service* or care or team*)) or ti,ab(case management)))

A.4.7 Cough

10. What is the clinical and cost-effectiveness of cough augmentation techniques for people with MND who have an ineffective cough?

Search constructed by combining the columns in the following table using the AND Boolean operator. Exclusion filter applied using NOT Boolean operator.

Population	Intervention or exposure	Comparison	Study design filter	Date parameters and other limits
Adults (aged 18 and over) with motor neurone disease (A.2.1) OR Neuromuscular disease (A.2.2)	Cough augmentation techniques			See Table 1 English only Exclusion filter applied in Medline, Embase and PsycINFO

Medline search terms

1.	cough/
2.	cough*.ti,ab.
3.	*respiratory therapy/ or *drainage, postural/
4.	(insufflat* or exsufflat*).ti,ab.
5.	postural drain*.ti,ab.
6.	((inhaling or inhalation or inhale or respiratory) adj2 therap*).ti,ab.
7.	percussion/
8.	((chest or lung) adj2 (percussion or resonance)).ti,ab.
9.	(lung adj2 volume).ti,ab.
10.	((breath* or air*) adj2 (stack* or technique*)).ti,ab.
11.	((air* or chest*) adj2 clear*).ti,ab.
12.	(inspiratory adj2 (exercise* or exercising)).ti,ab.
13.	or/1-12

Embase search terms

1.	exp *coughing/
2.	cough*.ti,ab.
3.	exp *artificial ventilation/
4.	exp *postural drainage/
5.	(insufflat* or exsufflat*).ti,ab.
6.	postural drain*.ti,ab.

7.	((inhaling or inhalation or inhale or respiratory) adj2 therap*).ti,ab.
8.	exp *percussion/
9.	((chest or lung) adj2 (percussion or resonance)).ti,ab.
10.	(lung adj2 volume).ti,ab.
11.	((breath* or air*) adj2 (stack* or technique*)).ti,ab.
12.	((air* or chest*) adj2 clear*).ti,ab.
13.	(inspiratory adj2 (exercise* or exercising)).ti,ab.
14.	or/1-13

Cochrane search terms

#1.	MeSH descriptor: [cough] explode all trees
#2.	cough*:ti,ab
#3.	MeSH descriptor: [respiratory therapy] explode all trees
#4.	MeSH descriptor: [drainage, postural] explode all trees
#5.	(insufflat* or exsufflat*):ti,ab
#6.	postural drain*:ti,ab
#7.	((inhaling or inhalation or inhale or respiratory) near/2 therap*):ti,ab
#8.	MeSH descriptor: [percussion] explode all trees
#9.	((chest or lung) near/2 (percussion or resonance)):ti,ab
#10.	(lung near/2 volume):ti,ab
#11.	((breath* or air*) near/2 (stack* or technique*)):ti,ab
#12.	((air* or chest*) near/2 clear*):ti,ab
#13.	(inspiratory near/2 (exercise* or exercising)):ti,ab
#14.	{or #1-#13}

CINAHL search terms

S1.	(MH "cough")
S2.	cough*
S3.	(MH "respiratory therapy+")
S4.	(MH "drainage, postural")
S5.	insufflat* or exsufflat*
S6.	postural drain*
S7.	inhaling n2 therap* or inhalation n2 therap* or inhale n2 therap* or respiratory n2 therap*
S8.	(MH "percussion")
S9.	chest n2 percussion or lung n2 percussion or lung n2 resonance or chest n2 resonance
S10.	breath* n2 stack* or breath* n2 technique or air* n2 stack* or air* n2 technique
S11.	air* n2 clear* or chest* n2 clear*
S12.	inspiratory n2 exercis*
S13.	S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9 or S10 or S11 or S12

A.4.8 Discontinuation of non-invasive ventilation (NIV)

11.What is the most appropriate management of discontinuation, at a patient's request, of NIV?

12.What factors influenced the experience of discontinuation, at a patient's request, of NIV for relatives/carers/healthcare/social care professionals?

Search constructed by combining the columns in the following table using the AND Boolean operator. Exclusion filter applied using NOT Boolean operator.

Population	Intervention or exposure	Comparison	Study design filter	Date parameters and other limits
Adults (aged 18 and over) with motor neurone disease (A.2.1)			Question 11 The following filter was used in Medline, Embase and PsycINFO only: OBS Question 12 The following filter was used in Medline, Embase, CINAHL and PsycINFO QUAL	See Table 1 English only Exclusion filter applied in Medline, Embase and PsycINFO

A.4.9   End of life

13.What are the most appropriate ways of communicating with and supporting people with MND and their families and carers to help them anticipate, and prepare for, end of life?

Search constructed by combining the columns in the following table using the AND Boolean operator. Exclusion filter applied using NOT Boolean operator.

Population	Intervention or exposure	Comparison	Study design filter	Date parameters and other limits
Adults (aged 18 and over) with motor neurone disease (A.2.1)	End of life		The following filters were used in Medline and Embase, CINAHL and PsycINFO only: QUAL	See Table 1 English only Exclusion filter applied in Medline, Embase and PsycINFO

Medline search terms

1.	death/
2.	(dying or die or dies or died or death).ti,ab.
3.	terminally ill/ or terminal care/ or palliative care/
4.	((terminal or palliati*) adj1 care).ti,ab.
5.	"terminally ill".ti,ab.
6.	"terminal illness".ti,ab.
7.	(palliati* adj1 stage*).ti,ab.
8.	("end of life" adj2 (stage or stages)).ti,ab.
9.	"end of life".ti,ab.
10.	((last or final) adj1 (hour* or day* or minute* or stage*)).ti,ab.
11.	((dying or terminal) adj1 phase*).ti,ab.
12.	((dying or terminal or end) adj1 stage*).ti,ab.
13.	(dying adj2 (actively or begin* or begun)).ti,ab.
14.	((death adj2 imminent*) or impending).ti,ab.
15.	(body adj2 (shut down or shutting down or deteriorat*)).ti,ab.
16.	deathbed.ti,ab.
17.	or/1-16

Embase search terms

1.	death/
2.	(dying or die or dies or died or death).ti,ab.
3.	terminally ill patient/ or terminal care/ or palliative therapy/
4.	((terminal or palliati*) adj1 care).ti,ab.
5.	"terminally ill".ti,ab.
6.	"terminal illness".ti,ab.
7.	(palliati* adj1 stage*).ti,ab.
8.	("end of life" adj2 (stage or stages)).ti,ab.
9.	"end of life".ti,ab.
10.	((last or final) adj1 (hour* or day* or minute* or stage*)).ti,ab.
11.	((dying or terminal) adj1 phase*).ti,ab.
12.	((dying or terminal or end) adj1 stage*).ti,ab.
13.	(dying adj2 (actively or begin* or begun)).ti,ab.
14.	((death adj2 imminent*) or impending).ti,ab.
15.	(body adj2 (shut down or shutting down or deteriorat*)).ti,ab.
16.	deathbed.ti,ab.
17.	or/1-16

CINAHL search terms

S1.	(MH "death+")
S2.	dying or die or dies or died or death
S3.	(MH "terminally ill patients+")
S4.	(MH "terminal care+")
S5.	(MH "palliative care")
S6.	terminal n1 care or palliati* n1 care
S7.	terminally ill or terminal illness
S8.	palliati* n1 stage*
S9.	end of life n2 stage or end of life n2 stages
S10.	end of life
S11.	last n1 hour* or last n1 day* or last n1 minute* or last n1 stage*
S12.	final n1 hour* or final n1 day* or final n1 minute* or final n1 stage*
S13.	dying n1 phase* or terminal n1 phase*
S14.	dying n1 stage* or terminal n1 stage* or end n1 stage*
S15.	dying n2 actively or dying n1 begin* or dying n1 begun
S16.	death n2 imminent* or death n2 impending*
S17.	body n2 shut down or body n2 shutting down or body n2 deteriorat*
S18.	deathbed
S19.	S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18

PsycINFO (OVID) search terms

1.	exp "death and dying"/
2.	(dying or die or dies or died or death).ti,ab.
3.	exp terminally ill patients/
4.	exp palliative care/
5.	((terminal or palliati*) adj1 care).ti,ab.

6.	"terminally ill".ti,ab.
7.	"terminal illness".ti,ab.
8.	(palliati* adj1 stage*).ti,ab.
9.	("end of life" adj2 (stage or stages)).ti,ab.
10.	"end of life".ti,ab.
11.	((last or final) adj1 (hour* or days* or minute* or stage*)).ti,ab.
12.	((dying or terminal) adj1 phase*).ti,ab.
13.	((dying or terminal or end) adj1 stage*).ti,ab.
14.	(dying adj2 (actively or begin* or begun)).ti,ab.
15.	((death adj2 imminent*) or impending).ti,ab.
16.	(body adj2 (shut down or shutting down or deteriorat*)).ti,ab.
17.	deathbed.ti,ab.
18.	or/1-17

PsycINFO (ProQuest) search terms

1.	su.exact.explode("death and dying") or ti,ab(dying or die or dies or died or death) or su.exact.explode("terminally ill patients") or su.exact.explode("palliative care") or ti,ab((terminal or palliati*) near/1 care) or ti,ab("terminally ill") or ti,ab("terminal illness") or ti,ab(palliati* near/1 stage*) or ti,ab("end of life" near/2 (stage or stages)) or ti,ab("end of life") or ti,ab((last or final) near/1 (hour* or days* or minute* or stage*)) or ti,ab((dying or terminal) near/1 phase*) or ti,ab((dying or terminal or end) near/1 stage*) or ti,ab(dying near/2 (actively or begin* or begun)) or ti,ab((death near/2 imminent*) or impending) or ti,ab(body near/2 (shut-down or shutting-down or deteriorat*)) or ti,ab(deathbed)

A.4.10 Equipment for muscle weakness

14. What are the equipment needs of people with MND for improving mobility and fulfilling activities of daily living due to muscle weakness?

Search constructed by combining the columns in the following table using the AND Boolean operator. Exclusion filter applied using NOT Boolean operator.

Population	Intervention or exposure	Comparison	Study design filter	Date parameters and other limits
Adults (aged 18 and over) with motor neurone disease (A.2.1)	Equipment aids for muscle weakness Terms not used in CINAHL search		The following filters were used in Medline, Embase and CINAHL only: QUAL	See Table 1 English only Exclusion filter applied in Medline and Embase

Medline search terms

1.	(mobil* adj4 (equip* or aid* or device*)).ti,ab.
2.	wheelchairs/
3.	(wheelchair* or wheel chair* or wheel-chair*).ti,ab.
4.	(mobil* adj3 scooter*).ti,ab.
5.	((head or neck or cervical or back) adj3 (collar* or support*)).ti,ab.
6.	patient lifting/
7.	(hoist* or lift*).ti,ab.
8.	exp posture/
9.	beds/
10.	(postur* adj3 support*).ti,ab.

11.	(bed* or mattress* or cushion* or seat* or chair* or pillow*).ti,ab.
12.	(riser* or reclin*).ti,ab.
13.	((arm* or shoulder*) adj3 support*).ti,ab.
14.	((eat* or drink*) adj3 (aid* or device* or equip*)).ti,ab.
15.	braces/ or splints/
16.	exp orthotic devices/
17.	(orthos#s or orthoti* or splint* or AFO or DAFO or brace*).ti,ab.
18.	walkers/ or canes/ or crutches/
19.	(walk* adj3 (stick* or frame* or troll*)).ti,ab.
20.	(cane* or crutch*).ti,ab.
21.	exp self-help devices/
22.	telemedicine/
23.	environmental control*.ti,ab.
24.	((assist* or communicat*) adj3 (technolog* or aid* or device* or equip*)).ti,ab.
25.	(ramp* or access* or adapt*).ti,ab.
26.	personal alarm*.ti,ab.
27.	or/1-26

Embase search terms

1.	(mobil* adj4 (equip* or aid* or device*)).ti,ab.
2.	exp *wheelchair/
3.	(wheelchair* or wheel chair* or wheel-chair*).ti,ab.
4.	(mobil* adj3 scooter*).ti,ab.
5.	((head or neck or cervical or back) adj3 (collar* or support*)).ti,ab.
6.	*patient lifting/
7.	(hoist* or lift*).ti,ab.
8.	*body posture/
9.	exp *bed/
10.	(postur* adj3 support*).ti,ab.
11.	(bed* or mattress* or cushion* or seat* or chair* or pillow*).ti,ab.
12.	(riser* or reclin*).ti,ab.
13.	((arm* or shoulder*) adj3 support*).ti,ab.
14.	((eat* or drink*) adj3 (aid* or device* or equip*)).ti,ab.
15.	exp *splint/
16.	exp *orthosis/
17.	(orthos#s or orthoti* or splint* or AFO or DAFO or brace*).ti,ab.
18.	exp *walking aid/
19.	(walk* adj3 (stick* or frame* or troll*)).ti,ab.
20.	(cane* or crutch*).ti,ab.
21.	*self help/
22.	*assistive technology/
23.	*communication aid/
24.	exp *telemedicine/
25.	((assist* or communicat*) adj3 (technolog* or aid* or device* or equip*)).ti,ab.
26.	(ramp* or access* or adapt*).ti,ab.

27.	environmental control*.ti,ab.
28.	personal alarm*.ti,ab.
29.	or/1-28

A.4.11 Frequency of assessment

15.What is the optimum frequency of assessment required to assess disease progression of MND?

Search constructed by combining the columns in the following table using the AND Boolean operator. Exclusion filter applied using NOT Boolean operator.

Population	Intervention or exposure	Comparison	Study design filter	Date parameters and other limits
Adults (aged 18 and over) with motor neurone disease (A.2.1)	Frequency of assessment		The following filters were used in Medline and Embase only: OBS, RCT, SR	See Table 1 English only Exclusion filter applied in Medline and Embase

Medline search terms

1.	time factors/
2.	"appointments and schedules"/
3.	(visit* adj5 clinic*).ti,ab.
4.	(optimal or routine* or regular or periodic* or review* or frequent* or time* or timing or week* or month* or year* or day* or recall*).ti,ab.
5.	(assess* or interval* or visit* or inspect* or examin* or attend* or check-up* or recall* or appointment*).ti,ab.
6.	4 and 5
7.	or/1-3,6

Embase search terms

1.	*time/
2.	*hospital management/
3.	(visit* adj5 clinic*).ti,ab.
4.	(optimal or routine* or regular or periodic* or review* or frequent* or time* or timing or week* or month* or year* or day* or recall*).ti,ab.
5.	(assess* or interval* or visit* or inspect* or examin* or attend* or check-up* or recall* or appointment*).ti,ab.
6.	4 and 5
7.	or/1-3,6

Cochrane search terms

#1.	MeSH descriptor: [time factors] explode all trees
#2.	MeSH descriptor: [appointments and schedules] explode all trees
#3.	(visit* near/5 clinic*):ti,ab
#4.	(optimal or routine* or regular or periodic* or review* or frequent* or time* or timing or week* or month* or year* or day* or recall*):ti,ab
#5.	(assess* or interval* or visit* or inspect* or examin* or attend* or check-up* or recall* or appointment*):ti,ab
#6.	#4 and #5
#7.	#1 or #2 or #3 or #6

A.4.12 Timing of gastronomy

16. What is the clinically appropriate timing of placement of a gastrostomy tube for nutrition management in people with MND?

Search constructed by combining the columns in the following table using the AND Boolean operator. Exclusion filter applied using NOT Boolean operator.

Population	Intervention or exposure	Comparison	Study design filter	Date parameters and other limits
Adults (aged 18 and over) with motor neurone disease (A.2.1)	Timing of gastronomy			See Table 1 English only Exclusion filter applied in Medline, Embase and PsycINFO

Medline search terms

1.	enteral nutrition/
2.	((enteral or enteric) adj2 (nutrition* or feed*)).ti,ab.
3.	gastrostomy/
4.	gastrostom*.ti,ab.
5.	((tube or tubes) adj2 (nutrition* or feed*)).ti,ab.
6.	(PEG or PIG or RIG).ti,ab.
7.	(gavage adj2 feed*).ti,ab.
8.	(tubing adj2 (nutrition* or feed*)).ti,ab.
9.	"g tube".ti,ab.
10.	(artificial adj2 feed*).ti,ab.
11.	or/1-10

Embase search terms

1.	enteric feeding/
2.	gastrostomy/
3.	((enteral or enteric) adj2 (nutrition* or feed*)).ti,ab.
4.	gastrostom*.ti,ab.
5.	((tube or tubes) adj2 (nutrition* or feed*)).ti,ab.
6.	(tubing adj2 (nutrition* or feed*)).ti,ab.
7.	(artificial adj2 feed*).ti,ab.
8.	(gavage adj2 feed*).ti,ab.
9.	(PEG or PIG or RIG).ti,ab.
10.	"g tube".ti,ab.
11.	or/1-10

Cochrane search terms

#1.	MeSH descriptor: [enteral nutrition] explode all trees
#2.	MeSH descriptor: [gastrostomy] explode all trees
#3.	((enteral or enteric) near/2 (nutrition* or feed*)):ti,ab
#4.	((tube or tubes or tubing) near/2 (nutrition* or feed*)):ti,ab
#5.	(gavage near/2 feed*):ti,ab
#6.	(artificial near/2 feed*) .ti,ab
#7.	gastrostom*:ti,ab

#8.	(PEG or PIG or RIG):ti,ab
#9.	g tube:ti,ab
#10.	{or #1-#9}

CINAHL search terms

S1.	(MM "enteral nutrition")
S2.	(MM "gastrostomy")
S3.	gastrostom*
S4.	PEG or PIG or RIG
S5.	g tube
S6.	enteral n2 nutrition* or enteral n2 feed* or enteric n2 nutrition* or enteric n2 feed*
S7.	tube n2 nutrition* or tube n2 feed* or tubes n2 nutrition* or tubes n2 feed* or tubing n2 nutrition* or tubing n2 feed*
S8.	gavage n2 feed* or artifical n2 feed*
S9.	S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8

PsycINFO (OVID) search terms

1.	exp nutrition/ or exp food intake/
2.	gastrostom*.ti,ab.
3.	(PEG or PIG or RIG).ti,ab.
4.	"g tube".ti,ab.
5.	((enteral or enteric) adj2 (nutrition* or feed*)).ti,ab.
6.	((tube or tubes or tubing) adj2 (nutrition* or feed*)).ti,ab.
7.	(gavage adj2 feed*).ti,ab.
8.	(artificial adj2 feed*).ti,ab.
9.	or/1-8

PsycINFO (ProQuest) search terms

| 1. | su.exact.explode("nutrition") or su.exact.explode("food intake") or ti,ab(gastrostom*.ti,ab) or ti,ab(peg or pig or rig) or ti,ab("g tube") or ti,ab((enteral or enteric) near/2 (nutrition* or feed*)) or ti,ab((tube or tubes or tubing) near/2 (nutrition* or feed*)) or ti,ab(gavage near/2 feed*) or ti,ab(artificial adj2 feed*) |

A.4.13 Knowledge for the communication of diagnosis

See A.4.2

A.4.14 Muscle weakness

Searches for the following two questions were run as one search:

17. For adults with MND, what is the clinical and cost-effectiveness of non-pharmacological treatments for muscle cramps and fasciculations, increased tone (including spasticity, muscle spasm or stiffness), muscle stiffness, wasting or atrophy?

18. For adults with MND, what is the clinical and cost-effectiveness of pharmacological treatments for muscle cramps and fasciculations, increased tone, muscle weakness, wasting or atrophy?

Search constructed by combining the columns in the following table using the AND Boolean operator. Exclusion filter applied using NOT Boolean operator.

Population	Intervention or exposure	Comparison	Study design filter	Date parameters and other limits

Population	Intervention or exposure	Comparison	Study design filter	Date parameters and other limits
Adults (aged 18 and over) with motor neurone disease (A.2.1)	Pharmacological and non-pharmacological treatments for muscle weakness		The following filters were used in Medline and Embase only: OBS, RCT, SR	See Table 1 English only Exclusion filter applied in Medline and Embase

Medline search terms

1.	baclofen/ or diazepam/ or clonazepam/ or dantrolene/ or memantine/
2.	(baclofen* or baclophen or lioresal or diazepam or rimapan or tensium or dialar or diazemuls or clonazepam or rivotil or dantrolene or dantrium or tizanidine or zanaflex or tetrazepam or memantine or ebixa).ti,ab.
3.	exp botulinum toxins/
4.	(botulinum adj3 (a or b or toxin*)).ti,ab.
5.	(dysport or botox or btx or oculinum or xeomin or reloxin or prosigne or purtox or nt201 or mybloc or neurobloc).ti,ab.
6.	transcutaneous electric nerve stimulation/
7.	((function* or neuromuscul* or peripheral* or transcutan* or electric*) adj4 stimulat*).ti,ab.
8.	TENS.ti,ab.
9.	ultrasonography/
10.	(sonograph* or ultrasound* or ultrason*).ti,ab.
11.	exp physical therapy modalities/
12.	exp exercise/
13.	(physiotherap* or exercis* or stretch* or resist* or position*).ti,ab.
14.	(physical adj2 therap*).ti,ab.
15.	muscle cramp/ or muscle rigidity/ or muscle spasticity/ or muscle weakness/
16.	((muscle* or muscular) adj2 (cramp* or rigid* or spast* or weak* or tight* or stiff* or twitch* or spasm*)).ti,ab.
17.	(fasciculat* or contract*).ti,ab.
18.	transcranial magnetic stimulation/
19.	((transcran* or intramusc*) adj4 stimulat*).ti,ab.
20.	(gabapentin or neurontin).ti,ab.
21.	or/1-20

Embase search terms

1.	*baclofen/ or *diazepam/ or *clonazepam/ or *dantrolene/ or *memantine/ or *tizanidine/ or *tetrazepam/
2.	(baclofen* or baclophen or lioresal or diazepam or rimapan or tensium or dialar or diazemuls or clonazepam or rivotil or dantrolene or dantrium or tizanidine or zanaflex or tetrazepam or memantine or ebixa).ti,ab.
3.	*botulinum toxin/ or *botulinum toxin e/ or *botulinum toxin f/
4.	*botulinum toxin b/ or *botulinum toxin a/
5.	(botulinum adj3 (a or b or toxin*)).ti,ab.
6.	(dysport or botox or btx or oculinum or xeomin or reloxin or prosigne or purtox or nt201 or mybloc or neurobloc).ti,ab.
7.	*transcutaneous nerve stimulation/
8.	((function* or neuromuscul* or peripheral* or transcutan* or electric*) adj4 stimulat*).ti,ab.

9.	TENS.ti,ab.
10.	*echography/
11.	(sonograph* or ultrasound* or ultrason*).ti,ab.
12.	exp *physiotherapy/
13.	exp *exercise/
14.	(physiotherap* or exercis* or stretch* or resist* or position*).ti,ab.
15.	(physical adj2 therap*).ti,ab.
16.	transcranial magnetic stimulation/
17.	((transcran* or intramusc*) adj4 stimulat*).ti,ab.
18.	(gabapentin or neurontin).ti,ab.
19.	*muscle cramp/ or *muscle rigidity/ or *muscle weakness/ or *spasticity/
20.	((muscle* or muscular) adj2 (cramp* or rigid* or spast* or weak* or tight* or stiff* or twitch* or spasm*)).ti,ab.
21.	(fasciculat* or contract*).ti,ab.
22.	or/1-21

Cochrane search terms

#1.	MeSH descriptor: [baclofen] explode all trees
#2.	MeSH descriptor: [diazepam] explode all trees
#3.	MeSH descriptor: [clonazepam] explode all trees
#4.	MeSH descriptor: [dantrolene] explode all trees
#5.	MeSH descriptor: [memantine] explode all trees
#6.	(baclofen* or baclophen or lioresal or diazepam or rimapan or tensium or dialar or diazemuls or clonazepam or rivotil or dantrolene or dantrium or tizanidine or zanaflex or tetrazepam or memantine or ebixa):ti,ab
#7.	MeSH descriptor: [botulinum toxins] explode all trees
#8.	(botulinum near/3 (a or b or toxin*)):ti,ab
#9.	(dysport or botox or btx or oculinum or xeomin or reloxin or prosigne or purtox or nt201 or mybloc or neurobloc):ti,ab
#10.	MeSH descriptor: [transcutaneous electric nerve stimulation] explode all trees
#11.	((function* or neuromuscul* or peripheral* or transcutan* or electric*) near/4 stimulat*):ti,ab
#12.	TENS:ti,ab
#13.	MeSH descriptor: [ultrasonography] explode all trees
#14.	(sonograph* or ultrasound* or ultrason*):ti,ab
#15.	MeSH descriptor: [physical therapy modalities] explode all trees
#16.	MeSH descriptor: [exercise] explode all trees
#17.	(physiotherap* or exercis* or stretch* or resist* or position*):ti,ab
#18.	(physical near/2 therap*):ti,ab
#19.	MeSH descriptor: [muscle cramp] explode all trees
#20.	MeSH descriptor: [muscle rigidity] explode all trees
#21.	MeSH descriptor: [muscle spasticity] explode all trees
#22.	MeSH descriptor: [muscle weakness] explode all trees
#23.	((muscle* or muscular) near/2 (cramp* or rigid* or spast* or weak* or tight* or stiff* or twitch* or spasm*)):ti,ab
#24.	(fasciculat* or contract*):ti,ab
#25.	MeSH descriptor: [transcranial magnetic stimulation] explode all trees
#26.	((transcran* or intramusc*) near/4 stimulat*):ti,ab

#27.	(gabapentin or neurontin):ti,ab
#28.	{#1-#27}

CINAHL search terms

S1.	baclofen* or baclophen or lioresal or diazepam or rimapan or tensium or dialar or diazemuls or clonazepam or rivotil or dantrolene or dantrium or tizanidine or zanaflex or tetrazepam or memantine or ebixa
S2.	(MH "botulinum toxins")
S3.	botulinum n3 a OR botulinum n3 b OR botulinum n3 toxin*
S4.	dysport or botox or btx or oculinum or xeomin or reloxin or prosigne or purtox or nt201 or mybloc or neurobloc
S5.	(MH "transcutaneous electric nerve stimulation")
S6.	function* n4 stimulat* or neuromuscul* n4 stimulat* or peripheral* n4 stimulat* or transcutan* n4 stimulat* or electric* n4 stimulat*
S7.	tens
S8.	(MH "ultrasonography+")
S9.	sonograph* or ultrasound* or ultrason*
S10.	(MH "physical therapy+")
S11.	(MH "exercise+")
S12.	physiotherap* or exercis* or stretch* or resist* or position*
S13.	physical n2 therap*
S14.	(MH "muscle cramp")
S15.	(MH "muscle weakness")
S16.	(MH "muscle spasticity")
S17.	musc* n2 cramp* or musc* adj2 rigid* or musc* adj2 spast* or musc* adj2 weak* or musc* adj2 tight* or musc* adj2 stiff* or musc* adj twitch* or musc* adj2 spasm*
S18.	fasciculat* or contract*
S19.	transcran* n4 stimulat* or intramusc* n4 stimulat*
S20.	(MH "gabapentin")
S21.	gabapentin or neurontin
S22.	S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18 or S19 or S20 or S21

A.4.15   Nutrition

See A.4.1

A.4.16   Psychological support

See A.4.2

A.4.17   Risk factors

Searches for the following two questions were run as one search:

19. What are the most accurate prognostic tools for estimating survival in people with MND?

20. What risk factors predict survival in people with MND?

Search constructed by combining the columns in the following table using the AND Boolean operator and by combining the rows using the OR Boolean operator. Exclusion filter applied using NOT Boolean operator.

Search	Population	Intervention or exposure	Study design filter	Date parameters and other limits
A	Adults (aged 18 and over) with motor neurone disease (A.2.1)	Risk factors		See Table 1 English only Exclusion filter applied in Medline and Embase
B	Same as search A		The following filters were used in Medline and Embase only: OBS	Same as search A

Medline search terms

1.	exp risk/
2.	disease progression/
3.	"amyotrophic lateral sclerosis functional rating scale".ti,ab.
4.	alsfrs*.ti,ab.
5.	(measur* adj2 scale*).ti,ab.
6.	body weight changes/ or exp weight loss/ or body mass index/
7.	(weight adj2 (los* or reduc*)).ti,ab.
8.	(body mass index or bmi).ti,ab.
9.	exp respiratory function tests/
10.	((respiratory or pulmonary or lung) adj3 test*).ti,ab.
11.	exp vital capacity/
12.	exp forced expiratory flow rates/ or forced expiratory volume/
13.	(("sniff nasal inspiratory pressure" or "maximal inspiratory pressure" or "maximal expiratory pressure" or "forced vital capacity" or "forced expiratory volume") adj6 test*).ti,ab.
14.	(peak expiratory flow* or peak flow*).ti,ab.
15.	peak expiratory flow rate/
16.	((force* or time*) adj vital capacit*).ti,ab.
17.	(forced expiratory adj3 (flow* or rat* or vol*)).ti,ab.
18.	exp cough/
19.	cough*.ti,ab.
20.	or/1-19
21.	(death* or dying or died or deceas* or mortalit* or surviv*).ti,ab.
22.	mortality/ or survival rate/
23.	survival analysis/ or survival/
24.	mo.fs.
25.	or/21-24
26.	20 and 25

Embase search terms

1.	exp *disease course/
2.	"amyotrophic lateral sclerosis functional rating scale".ti,ab.
3.	alsfrs*.ti,ab.
4.	(measur* adj2 scale*).ti,ab.
5.	*body mass/
6.	*weight change/

7.	exp *weight reduction/
8.	(weight adj2 (los* or reduc*)).ti,ab.
9.	(body mass index or bmi).ti,ab.
10.	exp *lung function test/
11.	((respiratory or pulmonary or lung) adj3 test*).ti,ab.
12.	*vital capacity/
13.	*forced expiratory volume/
14.	*expiratory flow rate/ or *peak expiratory flow/
15.	(("sniff nasal inspiratory pressure" or "maximal inspiratory pressure" or "maximal expiratory pressure" or "forced vital capacity" or "forced expiratory volume") adj6 test*).ti,ab.
16.	(peak expiratory flow* or peak flow*).ti,ab.
17.	((force* or time*) adj vital capacit*).ti,ab.
18.	(forced expiratory adj3 (flow* or rat* or vol*)).ti,ab.
19.	exp coughing/
20.	cough.ti,ab.
21.	exp *risk/
22.	or/1-21
23.	(death* or dying or died or deceas* or mortalit* or surviv*).ti,ab.
24.	*mortality/
25.	*survival/ or *survival time/ or *survival prediction/ or *survival factor/
26.	or/23-25
27.	22 and 26

A.4.18 Saliva

21.What is the clinical and cost-effectiveness of interventions for saliva management in people with MND?

Search constructed by combining the columns in the following table using the AND Boolean operator. Exclusion filter applied using NOT Boolean operator.

Population	Intervention or exposure	Comparison	Study design filter	Date parameters and other limits
Adults (aged 18 and over) with swallowing problems caused by neurological disorders	Saliva management		The following filters were used in Medline and Embase only: RCT, SR	See Table 1 English only Exclusion filter applied in Medline and Embase

Medline search terms

1.	cerebral palsy/
2.	parkinson disease/
3.	exp multiple system atrophy/
4.	supranuclear palsy, progressive/
5.	little* disease*.ti,ab.
6.	((cerebral or brain or central) adj2 (pals* or paralysis)).ti,ab.
7.	spastic diplegi*.ti,ab.
8.	parkinson* disease*.ti,ab.

9.	hypokinetic rigid syndrome*.ti,ab.
10.	paralysis agitans.ti,ab.
11.	primary parkinsonism.ti,ab.
12.	multiple system atroph*.ti,ab.
13.	olivopontocerebellar atroph*.ti,ab.
14.	shy-drager* syndrome*.ti,ab.
15.	striatonigral degeneration.ti,ab.
16.	((multi-system* or multisystem*) adj atroph*).ti,ab.
17.	((corticobasal or cortico-basal) adj2 (syndrome* or degeneration*)).ti,ab.
18.	(progressive supranuclear adj2 (pals* or ophthalmoplegi*)).ti,ab.
19.	(richardson* adj2 (syndrome* or disease*)).ti,ab.
20.	or/1-19
21.	saliva/
22.	salivation/
23.	salivary glands/
24.	sialorrhea/
25.	saliva*.ti,ab.
26.	sialorrhea*.ti,ab.
27.	ptyalis*.ti,ab.
28.	(hypersaliva* or hyper-saliva*).ti,ab.
29.	drool*.ti,ab.
30.	phlegm.ti,ab.
31.	mucus.ti,ab.
32.	dribbl*.ti,ab.
33.	sialorrhoea*.ti,ab.
34.	or/21-33
35.	20 and 34

Embase search terms

1.	cerebral palsy/
2.	exp parkinson disease/
3.	shy drager syndrome/
4.	progressive supranuclear palsy/
5.	corticobasal degeneration/
6.	little* disease*.ti,ab.
7.	((cerebral or brain or central) adj2 (pals* or paralysis)).ti,ab.
8.	spastic diplegi*.ti,ab.
9.	parkinson* disease*.ti,ab.
10.	hypokinetic rigid syndrome*.ti,ab.
11.	paralysis agitans.ti,ab.
12.	primary parkinsonism.ti,ab.
13.	multiple system atroph*.ti,ab.
14.	olivopontocerebellar atroph*.ti,ab.
15.	shy-drager* syndrome*.ti,ab.
16.	striatonigral degeneration.ti,ab.

17.	((multi-system* or multisystem*) adj atroph*).ti,ab.
18.	((corticobasal or cortico-basal) adj2 (syndrome* or degeneration*)).ti,ab.
19.	(progressive supranuclear adj2 (pals* or ophthalmoplegi*)).ti,ab.
20.	(richardson* adj2 (syndrome* or disease*)).ti,ab.
21.	or/1-20
22.	*saliva/
23.	*salivation/
24.	exp *hypersalivation/
25.	exp *salivary gland/
26.	saliva*.ti,ab.
27.	sialorrhea*.ti,ab.
28.	ptyalis*.ti,ab.
29.	(hypersaliva* or hyper-saliva*).ti,ab.
30.	drool*.ti,ab.
31.	phlegm.ti,ab.
32.	mucus.ti,ab.
33.	dribbl*.ti,ab.
34.	sialorrhoea*.ti,ab.
35.	or/22-34
36.	21 and 35

Cochrane search terms

#1.	[MeSH "cerebral palsy"]
#2.	[MeSH "parkinson disease"]
#3.	[MeSH "multiple system atrophy"]
#4.	[MeSH "supranuclear palsy, progressive"]
#5.	little* disease*:ti,ab
#6.	((cerebral or brain or central) near/2 (pals* or paralysis)):ti,ab
#7.	spastic diplegi*:ti,ab
#8.	parkinson* disease*:ti,ab
#9.	hypokinetic rigid syndrome*:ti,ab
#10.	paralysis agitans:ti,ab
#11.	primary parkinsonism:ti,ab
#12.	multiple system atroph*:ti,ab
#13.	olivopontocerebellar atroph*:ti,ab
#14.	shy-drager* syndrome*:ti,ab
#15.	striatonigral degeneration:ti,ab
#16.	((multi-system* or multisystem*) near atroph*):ti,ab
#17.	((corticobasal or cortico-basal) near/2 (syndrome* or degeneration*)):ti,ab
#18.	(progressive supranuclear) near/2 (pals* or ophthalmoplegi*):ti,ab
#19.	(richardson* near/2 (syndrome* or disease*)):ti,ab
#20.	{or #1-#19}
#21.	[MeSH saliva]
#22.	[MeSH salivation]
#23.	[MeSH "salivary glands"]

#24.	[MeSH sialorrhea]
#25.	saliva*:ti,ab
#26.	sialorrhea*:ti,ab
#27.	sialorrhoea*:ti,ab
#28.	ptyalis*:ti,ab
#29.	(hypersaliva* or hyper-saliva*):ti,ab
#30.	drool*:ti,ab
#31.	phlegm:ti,ab
#32.	mucus:ti,ab
#33.	dribbl*:ti,ab
#34.	{or #21-#33}
#35.	#20 and #34

A.4.19 Social care

See A.4.2

A.4.20 Timeliness of diagnosis

See A.4.2

A.5 Health economics search

The standard populations (A.2.1) for Medline and Embase were used unless stated otherwise.

A.5.1 Health economic reviews

Economic searches were conducted in Medline, Embase, HEED and CRD for NHS EED and HTA.

Population	Intervention or exposure	Comparison	Study design filters	Date parameters and other limits
Adults (aged 18 and over) with motor neurone disease (A.2.1)	n/a	n/a	The following filters were used in Medline and Embase only: HE	Medline and Embase 2012–18/05/2015 CRD EED and HTA Inception–18/05/2015 HEED Inception-19/08/2013 English only

CRD search terms

#1.	MeSH descriptor motor neuron disease explode all trees
#2.	MeSH descriptor amyotrophic lateral sclerosis explode all trees
#3.	MeSH descriptor bulbar palsy, progressive explode all trees
#4.	(motor neuron*) or (motorneuron*) or (moto neuron*) or (motoneuron*) or (moto-neuron*) or (motor-neuron*)
#5.	(pseudopolyneur*) or (pseudo-polyneur*) or (psuedo polyneur*)
#6.	(lateral adj scleros*) or (muscular adj atroph*) or (bulbar adj pals*)
#7.	(((bulbar or respirat* or limb) adj onset*))

#8.	(gehrig*)
#9.	(anterior adj (horn* or column)) or (ventral adj (horn or column))
#10.	((flail* adj (arm* or leg*)))
#11.	(guam adj disease*) or (guam adj disorder*) or (guam adj syndrome*)
#12.	(monomelic and amyotroph*)
#13.	MeSH descriptor frontotemporal dementia explode all trees
#14.	(frontotemporal adj dement*) or (fronto temporal adj dement*) or (fronto-temporal adj dement*)
#15.	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14

HEED search terms

1.	AX=motor and neuron*
2.	AX=motor neuron* or moto neuron* or motoneuron* or motorneuron* or moto-neuron* or motor-neuron*
3.	AX=lateral and scleros*
4.	AX=muscular and atroph*
5.	AX=bulbar and pals*
6.	AX=pseudopolyneur* or pseudo-polyneur* or psuedo polyneur*
7.	AX=gehrig*
8.	AX='bulbar onset' within 3
9.	AX='respiratory onset' within 3
10.	AX='limb onset' within 3
11.	AX=anterior and horn
12.	AX=anterior and column
13.	AX=ventral and horn
14.	AX=ventral and column
15.	AX=flail* and arm*
16.	AX=flail* and leg*
17.	AX=guam and disease
18.	AX=monomelic and amyotroph*
19.	AX=frontotemporal or fronto temporal or fronto-temporal
20.	CS=1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19

A.5.2 Quality of life reviews

Quality of life searches were conducted in Medline and Embase only

Population	Intervention or exposure	Comparison	Study design filters	Date parameters and other limits
Adults (aged 18 and over) with motor neurone disease (A.2.1)	n/a	n/a	The following filters were used in Medline and Embase only: QOL	Medline 1948-18/05/2015 Embase 1980–18/05/2015 English only

A.5.3 Breathlessness

Economic searches were conducted in Medline, Embase, HEED and CRD for NHS EED and HTA.

Population	Intervention or exposure	Comparison	Study design filters	Date parameters and other limits
	Pharmacological treatments for managing breathing difficulties	n/a	The following filters were used in Medline and Embase only: HE. MOD	Medline and Embase Inception - 18/05/2015 CRD EED and HTA Inception– 18/05/2015 HEED Inception- 22/05/2015 English only

Medline & Embase search terms

See A.4.4

CRD search terms

#1.	MeSH descriptor diazepam explode all trees
#2.	MeSH descriptor lorazepam explode all trees
#3.	MeSH descriptor midazolam explode all trees
#4.	MeSH descriptor clonazepam explode all trees
#5.	MeSH descriptor heroin explode all trees
#6.	MeSH descriptor morphine explode all trees
#7.	MeSH descriptor oxycodone explode all trees
#8.	MeSH descriptor fentanyl explode all trees
#9.	(diazepam or lorazepam or midazolam or rimapan or tensium or dialar of diazemuls)
#10.	(morphine or diamorphine or oxycodone or fentanyl or oramorph or sevredol or filnarine or morphgesic or mst continus or zomorph or mxl or cyclimorph or oxynorm or dolocodon or longtec or oxycontin or targinact or abstral or effentora or actiq or instanyl or pecfent or fencino or fentalis or matrifen or mezolar or osmanil or tilofyl or victanyl or durogesic or clonazepam or rivotil)
#11.	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10
#12.	MeSH descriptor dyspnea explode all trees
#13.	(dyspnea or dyspnoea)
#14.	(breathlessness)
#15.	(((difficult* or labor* or labour or short*) adj2 breath*))
#16.	#12 or #13 or #14 or #15
#17.	#11 and #16

HEED search terms

1.	AX=diazepam or lorazepam or midazolam or rimapan or tensium or dialar of diazemuls
2.	AX=morphine or diamorphine or oxycodone or fentanyl or oramorph or sevredol or filnarine or morphgesic or mst continus
3.	AX=zomorph or mxl or cyclimorph or oxynorm or dolocodon or longtec or oxycontin or targinact or abstral or effentora
4.	AX=actiq or instanyl or pecfent or fencino or fentalis or matrifen or mezolar or osmanil or tilofyl or victanyl
5.	AX=durogesic or clonazepam or rivotil

6.	CS=1 or 2 or 3 or 4 or 5
7.	AX=dyspnea or dyspnoea
8.	AX=breathlessness
9.	AX=shortage and breath
10.	AX=difficulty and breathing
11.	AX=difficulties and breathing
12.	AX=laboured and breathing
13.	AX=labored and breathing
14.	CS=7 or 8 or 9 or 10 or 11 or 12 or 13
15.	CS=6 and 14

A.5.4 Saliva

Economic searches were conducted in Medline, Embase, HEED and CRD for NHS EED and HTA.

Population	Intervention or exposure	Comparison	Study design filters	Date parameters and other limits
Adults (aged 18 and over) with swallowing problems caused by neurological disorders	Saliva management	n/a	The following filters were used in Medline and Embase only: HE	Medline and Embase All years-18/05/2015 CRD EED and HTA Inception–18/05/2015 HEED Inception-09/07/2015 English only

Medline & Embase search terms

See A.4.18

CRD search terms

#1.	MeSH descriptor cerebral palsy explode all trees
#2.	MeSH descriptor parkinson disease explode all trees
#3.	MeSH descriptor multiple system atrophy explode all trees
#4.	MeSH descriptor supranuclear palsy, progressive explode all trees
#5.	(little* disease*)
#6.	(((cerebral or brain or central) adj2 (pals* or paralysis)))
#7.	(spastic diplegi*)
#8.	(parkinson* disease*)
#9.	(hypokinetic rigid syndrome*)
#10.	(paralysis agitans)
#11.	(primary parkinsonism)
#12.	(multiple system atroph*)
#13.	(olivopontocerebellar atroph*)
#14.	(shy-drager* syndrome*)
#15.	(striatonigral degeneration)
#16.	(((multi-system* or multisystem*) adj atroph*))
#17.	(((corticobasal or cortico-basal) adj2 (syndrome* or degeneration*)))

#18.	((progressive supranuclear adj2 (pals* or ophthalmoplegi*)))
#19.	((richardson* adj2 (syndrome* or disease*)))
#20.	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19
#21.	MeSH descriptor saliva explode all trees
#22.	MeSH descriptor salivation explode all trees
#23.	MeSH descriptor salivary glands explode all trees
#24.	MeSH descriptor sialorrhea explode all trees
#25.	(saliva*)
#26.	(sialorrhea*)
#27.	(ptyalis*)
#28.	((hypersaliva* or hyper-saliva*))
#29.	(drool*)
#30.	(phlegm)
#31.	(mucus)
#32.	(dribbl*)
#33.	(sialorrhoea*)
#34.	#21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33
#35.	#20 and #34

HEED search terms

1.	AX=palsy or palsies
2.	AX=parkinson*
3.	AX=atroph*
4.	AX=little's and disease*
5.	AX=cerebral and paralysis
6.	AX=brain and paralysis
7.	AX=central and paralysis
8.	AX=spastic and diplegi*
9.	AX=hypokinetic rigid syndrome
10.	AX=paralysis agitans
11.	AX=olivopontocerebellar
12.	AX=shy-drager
13.	AX=striatonigral degeneration
14.	AX=corticobasal or cortico-basal
15.	AX=progressive supranuclear
16.	AX=richardson
17.	CS=1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
18.	AX=saliva*
19.	AX=sialorrhea
20.	AX=ptyalis*
21.	AX=hypersaliva* or hyper-saliva*
22.	AX=drool*
23.	AX=phlegm*
24.	AX=mucus*
25.	AX=dribbl*

| 26. | CS=18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 |
| 27. | CS=17 and 26 |

A.6 References